Parental experiences of adolescent cancer-related distress: A qualitative study

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Acknowledgements

This study was supported by University Hospitals Bristol NHS Foundation Trust and the Psychology Department at the University of Bath. A huge thank you to the parents who took the time to participate in this study and shared their experiences. We would also like to give thanks to the health and social care professionals at University Hospitals Bristol NHS Foundation Trust for supporting recruitment.

Data Availability Statement

There is no data available due to ethical restrictions.

Conflict of Interest

The authors declare no conflict of interest.

Funding Statement

Dr Loades is funded by the National Institute for Health Research (NIHR Doctoral Research Fellowship, DRF-2016-09-021). This report is independent research. The views expressed in this publication are those of the authors(s) and not necessarily those of the NHS, NIHR or the Department of Health and Social Care.

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Abstract

Objective: Adolescents' cancer-related distress is more complex, severe, and long-lasting than that of children and adults. Parents adopt an active role in supporting their adolescent, reporting that adolescent cancer-related distress is the most problematic symptom parents experience. Research has predominantly focused on exploring adolescents' experiences of cancer-related distress, with little attention to how their parent's experience their adolescent's cancer-related distress. Therefore, we aimed to explore parents' experiences of distress within the context of parenting an adolescent with cancer-related distress during, or immediately subsequent to active treatment.

Methods: 21 semi-structured interviews were conducted face-to-face or via telephone, with parents of adolescents aged 12-18 years from South-West England. Inductive reflexive thematic analysis was used to analyse the data.

Results: Three themes were generated: *'The contagion of distress,' 'Navigating breaking point,'* and *'Developmental disruption.'* Parental distress transcended from adolescent cancer-related distress, eliciting uncertainty, and challenging parenting limits. Parental distress was perpetuated by feelings that their adolescent had missed out on 'normal' adolescence during, and just after active treatment.

Conclusion: Parental distress reflected the multi-faceted nature of their adolescent's cancer-related distress. Findings advocate the importance of providing a parental voice within adolescent oncology populations. Developing tailored interventions to address parental distress are suggested.

Keywords: cancer-related distress; parental distress; adolescent cancer

Introduction

Living with cancer, from diagnosis to subsequent invasive treatments, is distressing (Burgoyne et al., 2015). A meta-analysis has shown that between 12%-42% of adolescent and young adult cancer patients on treatment or recently off-treatment report distress at some stage during the cancer trajectory (Sansom-Daly & Wakefield, 2013). Distress increases mortality risk and often presents as periods of increased worry, feelings of vulnerability and fears about the future (Barry et al., 2020). Normatively, adolescence is a stage characterised by the development of autonomy, independence from the family and increased levels of emotional distress (Romeo, 2013). Adolescents with cancer tend to experience more complex and long-lasting distress compared to children and adults (Sansom-Daly & Wakefield 2013). Parenting during adolescence is inherently challenging, and adolescent cancer and the associated distress is likely to impose additional parenting challenges, yet little is known how parents experience their adolescent's cancer-related distress.

Parents actively support their adolescent with cancer throughout the cancer trajectory by advocating for their adolescent through the cancer trajectory, making treatment-related decisions and providing emotional support to their adolescent child (Mack et al., 2019; McNeil et al., 2019; Pennant et al., 2020). Parents have described their adolescent's cancer-related distress as the most problematic symptom, contributing to symptom-burden on both the adolescent and parent themselves (Pöder et al., 2010). Adolescent cancer-related distress is likely to impact on parents in numerous ways. The burden of adolescent distress on parents may result in feelings of fear, uncertainty, and hopelessness due to adjusting to their adolescent's cancer experience whilst simultaneously supporting their adolescent (Schubart et al., 2008). Active treatment in adolescents is likely to restrict the evolving independence hindering peer relationships, leading to isolation and an over-dependency on their parents, against their expected developmental trajectory (Docherty et al., 2015).

Within the context of paediatric oncology, a recent meta-analysis indicated that high levels of parental distress were associated with high levels of their child's cancer-related distress (Bakula et al., 2019). The high concordance in distress levels between parents and children may be due to the cancer experience perpetuated by increased contact with the child and the parent's ability to cope (Okado et al., 2014). For instance, maternal distress is associated with their child's ability to cope with cancer-related distress (Monti et al., 2017). Assuming these findings apply directly to adolescents, disregards the developmental differences between children and adolescents, potentially influencing the cancer trajectory (Bakula et al., 2019).

Previous research has predominantly focused on exploring adolescents' experiences of cancer-related distress, with little attention to their parents' experiences of distress. Qualitative methods adopt an idiographic rather than a nomothetic approach, enabling the study of the specific rather than the general (Campbell et al., 2007; Joffe, 2012). Therefore, our aim was to use qualitative methods to study parental experiences of adolescent cancer-related distress in detail during and just after active treatment.

Methods

Full ethical approval was given by the South West Frenchay Research Ethics Committee (reference 18/SW/0222), IRAS (reference 242292) and the University of Bath.

Participants

Recruitment took place within a UK paediatric oncology service and teenage and young adult service in University Hospitals Bristol NHS Foundation Trust. Individuals were eligible to participate if they were parents/carers with adolescents (a) aged between 12 years and 18 years, diagnosed with cancer; (b) accessing care via the recruitment site; (c) receiving primary active treatment, or completed within one year of recruitment, or receiving maintenance treatment for acute lymphoblastic leukaemia. This timepoint reflects when

specialist oncology services are most involved with adolescents and parents, therefore providing opportunities for these services to support parents with their adolescent's cancer-related distress. All adolescents on treatment were receiving curative treatment and the experience of distress in adolescents or parents did not form part of the inclusion criteria.

The sample comprised 21 parents of 17 adolescents, of which 8 parents comprised 4 parenting dyads. All 6 fathers and 15 mothers were interviewed separately. In total, 11 adolescents were actively receiving treatment, and 6 had completed treatment. Participant demographics and clinical characteristics are shown in Table 1.

Table 1

Demographic and clinical characteristics of parents and adolescents

Characteristics	*M*	*SD*	Range
Age of parent (years)	48.33	3.69	42-57
Age of adolescent at diagnosis (years)	14.71	1.99	12-17
Age of adolescent at parent interview (years)	15.76	2.08	12-18
Treatment duration of adolescent undergoing active treatment (months)	7.36	6.04	2-24
Treatment duration of adolescent who completed active treatment (months)	10.83	8.28	4-27
Time since adolescent finished active treatment (months)	4.67	3.78	1-11
Characteristics	*n* (%)		
Gender of parent			
Male	6 (28.57)		
Female	15 (71.43)		
Gender of adolescent			
Male	4 (23.53)		
Female	13 (76.47)		
Type of cancer † ‡			
Brain tumour	2 (11.11)		
Germ cell	3 (16.67)		
Leukaemia	5 (27.78)		
Lymphoma	3 (16.67)		
Sarcoma	4 (22.22)		
Thyroid	1 (5.56)		

Type of cancer treatment	
Chemotherapy	16 (94.12)
Radiotherapy	1 (5.88)
Surgery	12 (70.59)

† One adolescent was previously diagnosed with leukaemia and had relapsed
‡ One adolescent was diagnosed with two cancer diagnoses: brain and germ cell tumour

Procedure

Recruitment took place between March and July 2019. Health and social care professionals working at the recruitment site identified potential eligible participants and provided them with information about the study. Twenty-six parents contacted the research team of these, 21 parents subsequently consented to the study, following which they took part in a semi-structured interview. The interview consisted of open-ended questions, which included questions designed to elicit parents' perceptions of their adolescent's cancer-related distress, fatigue, and pain (see Supplementary Information Table 1). The fatigue and pain topic areas formed additional research strands, as they were further common symptoms parents reported in their adolescent child's cancer experience. Due to the iterative nature, there was some flexibility in questioning to explore topics of interest.

Fifteen participants were interviewed face-to-face (8 interviews conducted at the parent's home, 1 interview at the parent's workplace and 6 interviews at the recruitment site hospital) and 6 over the telephone.

Two female MSc Health Psychology students (A.S and V.J) who were not known to the participants or part of the clinical team conducted the interviews. These students worked under supervision of a Clinical Psychologist (L.B) based at the recruitment site who provided 'managing distress training.' Interviews were digitally recorded, transcribed verbatim and anonymised at the point of transcription. Interview duration ranged between 18-80 minutes (M= 39, SD= 15).

Inductive reflexive thematic analysis was used as a structured approach to explore parental experiences, with the benefits of not being confined within a particular theoretical position (Braun & Clarke, 2019). Coding (completed by A.S) was an active, iterative process and themes were adapted and modified until they adequately captured the data. Data extracts were chosen that encompassed the essence of the theme in relation to the research aim and from across the sample to ensure they represented the sample.

The analytic approach was informed by a critical realist stance; we assumed that that knowledge is historically, socially and culturally situated and underpinned by theories that help us to get closer to an individual's reality, but do not determine their reality (Bhaskar, 2010; Fletcher, 2017). Therefore, we sought to understand parental distress through developing theories from parents' accounts of distress and their interpretations, to approximate parents' realities.

Qualitative approaches actively acknowledge the influence of the researcher on the research process (Yardley, 2008). To achieve dependability, clearly outlining the process of reflexive thematic analysis was considered to improve the research quality (Nowell et al., 2017; Tong et al., 2007). Clearly documenting reflexive thematic analysis improved rigor whilst providing the means to efficiently evaluate the trustworthiness of the research process (Nowell et al, 2017; Tong et al., 2007). To ensure transparency and coherence the interviewers maintained a reflexive journal providing critical accounts of the research process (Yardley, 2000, 2008). All interview transcriptions were checked for accuracy by another member of the research team.

Results

Parents described their experiences of adolescent's cancer-related distress during, or just after active treatment. Three overarching themes: *'The contagion of distress,'* *'Navigating breaking point,'* and *'Developmental disruption'* were developed and

accompanying verbatim quotations will be presented to illustrate each of the three themes (see the coding tree in Supplementary Information Table 2).

Theme 1: The contagion of distress.

Adolescent cancer-related distress frequently extended to the parents eliciting parental distress *"the whole experience is distressing, you know for everybody, you know, not just for [son]" Father of son (12 years; brain tumour on active treatment) (P20).* Adolescent cancer-related distress impacted the system they are in, therefore impacting their parents, which were acknowledged by the parent. However, for other parents, a sense of guilt was salient since they were not the one with cancer, eliciting a sense of uncertainty as to whether their distress was justified. *"Well actually it's not me that's got the illness really, should I be feeling as awful as I feel because I'm not actually the one that's ill?" Mother of daughter (17 years; lymphoma on active treatment) (P13)*. Parents described their adolescent's atypical mood swings, as expressions of adolescent distress, throughout cancer treatment. Parental narratives reflected the unpredictability of their adolescent's atypical mood swings, which generated parental uncertainty *"it can be difficult to know when her mood is going to change… you normally get warning signs and you don't when she's on the steroids, she just snaps which can be difficult to take" Father of daughter (16 years; lymphoma on active treatment) (P14).* These sudden distressed adolescent reactions indicated the frailty of the situation for both adolescents and parents, demonstrating the contagion of distress.

Parents described that when their adolescent experienced cancer-related distress, they often sought parental support. Parents felt responsible for managing their adolescent's distress and were doubtful to how they best support their child. When parents perceived that they could not adequately support their adolescent, they felt inadequate and distressed themselves *"when she cries I cry, I can't, I'm useless for her if, I mean, she had a real breakdown…she was just hanging onto me crying and I was hanging onto her crying, we*

were at my mum and dad's house…nobody knew what to do because I couldn't help her" Mother of daughter (18 years; thyroid cancer on active treatment) (P7). This mother absorbed her adolescent's distress in its entirety, reflecting the power of the distress contagion.

Theme 2: Navigating breaking point.

Collectively, parents expressed that managing their own distress was a low priority; they often were dismissive of their own distress, accepting that distress was an inevitable part of experiencing their adolescent's cancer *"we don't deal with it very well … I don't, I cry a lot" Mother of daughter (18 years; leukaemia on active treatment) (P17).* However, for other parents, there was an acceptance of parental distress yet a reluctance to seek support. Interestingly, there appeared to be a discrepancy between knowing what is helpful and doing what is helpful to manage their own parental distress. A sense of parental distress beyond parental control indicated that distraction and avoidance were helpful mechanisms to protect parents from the ever-present sense of being at breaking point *"I felt myself getting teary the other day and I changed the subject, whereas sometimes you need to get it out." Mother of son (12 years; brain tumour on active treatment) (P19).*

For some parents, their distress was lessened by the presence of their family and friends which provided reassurance of support if needed, consequently, increasing the distance from parents' breaking point *"I had enough people around I could've called upon. I'm very fortunate with my friends, family, I've got quite a good, really good network of friends 'n' family 'n' resources that I could pull upon." Father of son 15 years; leukaemia two-months post-treatment) (P3).* However, for other parents experiencing distress, utilising friends and family support was unhelpful due to managing the distress of others and increasing the emotional burden on parents. *"It's like, my friends and family, they don't really know what to say, and also like, every time you talk to them, they're virtually like,*

crying and I'm like, I don't really need that." Mother of Daughter (13 years; leukaemia on active treatment) (P4).

The threshold for parental distress was influenced by their adolescent's challenges with cancer treatment. Some parents felt that their adolescent was being coerced to continue with cancer treatment, which parents perceived as traumatic. This was largely due to the parents' potential encounter with their adolescent's mortality, despite their adolescent undergoing curative treatment *"there's no other way of saying, it just, it's just devastating to think your child doesn't want treatment so the obvious route would then be, she would have palliative care and she would die…" Mother of daughter (16 years; leukaemia on active treatment) (P1).* Mortality-related conversations between the parent and adolescent exceeded parent's own emotional and parental limits. Some parental interactions reflected an open and honest relationship with their adolescent. *"I know [daughter] struggled to deal with the fact that I was gonna be, I was emotional, and so talking about death with your child is actually really hard and I struggled with that" Mother of daughter (18 years; germ cell tumour 6-months post-treatment) (P10).*

Theme 3: Developmental disruption.

The negative impact of cancer and adolescent cancer-related distress on normative development contributed to their parent's distress. *"It's watching their independence and that the fact they can't just go to catch a bus with their friends … I think for [daughter] was heartbreaking at the time, so yes a very difficult time" Mother of daughter (15 years; osteosarcoma one-month post-treatment) (P12).*

During and just after active treatment, adolescents were increasingly dependent on parents to help manage adolescent distress and other symptoms. This sense of regressing back to a child was difficult for parents and typified by a sense of loss of parental independence and autonomy *"I felt like I was on maternity leave and that [daughter] had become my baby*

again because she was so needy and so vulnerable that she stopped being a 16-year old" Mother of daughter (17 years; sarcoma two-months post-treatment) (P2). Many parents felt that their child missed out on experiencing a 'normal' adolescence. Instead, parents described that their adolescent had accelerated into adulthood as a result of managing complex emotions and learning to navigate their distress *"I watched her change. She's grown up there's a loss of childhood, teenage years, I look at the child, the person before and it's very different to the person I see in front of me now…" Mother of daughter (18 years; sarcoma six-months post-treatment) (P5*). A sense of disconnection existed between the mother and her daughter due to the associated consequences of cancer treatment, resulting in a parental desire for the return of normalcy pre-diagnosis.

Discussion

By exploring parental experiences of their adolescent's cancer-related distress during and just after active treatment across a range of cancer types, we have highlighted how adolescent's distress negatively impacts parents and contributes to parental distress and feelings of inadequacy. Parents feeling unable to resolve the adolescent's distress, particularly regarding mortality, contributed to parental feelings of guilt and helplessness. Furthermore, parents varied in their response to their own distress; some parents were reluctant to confide in friends or family whilst for others, this was a source of support. Our study findings suggest differences between mothers and fathers regarding their perceptions of parental support available from their social network, for their own distress. Mothers perceived social support as inadequate as they tended to adopt another supporting role consequently increasing their emotional load. Parents frequently experienced feelings of loss arising from the negative impact of their adolescent's cancer-related distress on their child's life, and in some instances, longed for their adolescent to have a 'normal' adolescent life.

Our findings highlighted the interdependence of adolescent and parental distress. This is consistent with previous research which found an association between child and parental distress (Bakula et al., 2019). Parental involvement can impact their adolescent's clinical outcomes beyond survival, encompassing quality of life, self-esteem, participation in daily life and the ability to mature successfully into adulthood (Kazak et al., 2004; National Institute for Health and Care Excellence, 2005). Therefore, recognising and addressing parental distress as well as adolescent distress is likely to be important for clinical outcomes.

The parents in our study typically did not explicitly reveal their distress. This is consistent with other qualitative studies which have found that parents of children with cancer aged 3 years to 21 years have shown to suppress their feelings and prioritise their psychological well-being to focus on supporting their child despite these parents expressing a need for psychotherapy (Carlsson et al., 2019). However, adolescents and young people may misperceive their parent's avoidance of distress as low parental support, which has been associated with higher levels of adolescent distress (Kosir et al., 2019). To aid the recognition of parental distress, self-report screening measures should be explored (Haverman et al., 2013).

We found that parents talked about experiencing intense distress, particularly when their adolescent was faced with decisions about ceasing treatment and conversations about mortality. Parents are a key source of support for adolescents facing mortality-related issues (Hølge-Hazelton et al., 2016). Whilst parental distress has previously been recognised in parents of children and adolescents on palliative care pathways, it is important to expect that this might also be triggered during or just after active cancer treatment, even when prognosis is relatively good (Monterosso & Kristjanson, 2008; Collins et al., 2016).

Cancer was seen to have thwarted normal adolescent development and the process of gaining independence from the parents, which has also been reported in narratives of

adolescents with cancer (Reed-Berendt et al., 2019; Docherty et al., 2015). Parents in our study saw both regression to a dependent child state and acceleration to a responsible adult as a result of the cancer experience, contributing to the manifestation of parental distress. It is important to consider the dual-impact of cancer-related distress in adolescents and parents, as parents endorsing intense distress, consistent with post-traumatic stress disorder symptoms, have indicated a strong link with adolescent cancer-related distress (Kosir et al., 2019). To be able to provide parental support, parents may need more support for their own distress (Gutiérrez-Colina et al., 2017).

Strengths and limitations

A strength of this study included a focus on a rich exploration of parental experiences in the context of adolescent cancer and including both mothers and fathers. The findings reflect the importance of the parental role in supporting their adolescent child with cancer as this period in the lifespan already consists of developmental challenges. It provides recent findings advocating that parents require support and may not seek support from either friends, families or health and social care professionals. Therefore, highlighting the gap in the health and social care system to support these parents, for example understanding that mortality-related conversations are prevalent between parents and adolescents despite undergoing curative treatment.

We recruited parents of adolescents from one geographical region and parents that engaged with National Health Services. Furthermore, the clinical professionals acted as gatekeepers for this study therefore, the parents included may have had supportive relationships with health and social care professionals, likely to have influenced parental narratives of distress (Coyne et al., 2016). In future, studies could recruit from other sources such as via charitable organisations. Another limitation concerns variations between types of adolescent cancer diagnoses and the timepoint within their treatment plan which may have

elicited differing parental narratives. For example, this may have been dependent whether the parent's adolescent child was at the beginning of their treatment plan or approaching the end. However, this study may encourage further research exploring how parental experiences of distress and their adolescent's cancer-related distress differs across the cancer trajectory.

Research and clinical implications

Our study focused on experiences of parental distress within the context of their adolescent's cancer-related distress however, it is important to understand what influences parental experiences and how they cope, as they continue to be involved with their adolescent's health and social care (Zebrack, 2011; Walker et al., 2020). Prospective research should investigate the ways in which parental health beliefs, attitudes, and values contribute to parental distress within and across varying ethnic backgrounds or cultures, sexual orientations, and gender identities. Examining different methods of supporting parents of adolescents with cancer to manage their distress and that of their adolescent.

Clinicians working with parents of adolescents with cancer should routinely communicate openly with parents to improve their understanding and likely consequences of cancer-related distress for themselves and their adolescent child. For example, by providing distress psychoeducation. Health and social care professionals communicating through information leaflets and delivering cancer-related distress psychoeducation developed from these parents' narratives might be beneficial to help other parents learn about the symptoms of cancer-related distress and to validate parents' experiences during, or just after active treatment. Consequently, parents acquiring this knowledge may reduce further escalations of parental distress whilst strengthening their ability to manage their adolescent's cancer-related distress (Colletti et al., 2008; Stenberg et al., 2010). It is important to ensure that interventions are carefully developed by including adolescent and parents as stakeholders. Also, that parental interventions are sufficiently flexible to meet the needs of individual

adolescents who may be at different stages on the developmental pathway to autonomy and independence.

Conclusion

The current findings contributed new insights of parents' experiences of distress within the context of their adolescent's cancer-related distress during, and just after active treatment. Parents' distress manifested as their adolescent experienced cancer-related distress, particularly in relation to thwarted development and conversations about mortality. Although parental distress was evident, parents were less inclined to verbalise their own distress directly and may require support, space and encouragement to do so by health and social care professionals.

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Supporting Information

Supplementary Information Table 1

Semi-structured interview schedule

Interview questions
Tell me about your son's/daughter's illness and how it has affected your son/daughter?
How has it affected you? What impact does it have on daily life? How does it make you feel?
What impact does it have on the lives of others in your family?
Can you tell me about your son's/daughter's experience of fatigue?
How well do you feel you understand your son's/daughter's fatigue?
What have you found to be the most helpful ways of managing your child's fatigue?
Can you tell me about any resources or support that you have found beneficial or would have liked to have been offered around fatigue?
Can you tell me about your son's/daughter's experience of pain?
How well do you feel you understand your son's/daughter's pain?
What have you found to be the most helpful ways of managing your child's pain?
Can you tell me about any resources or support that you have found beneficial or would have liked to have been offered around pain?
Can you tell me about your son's/daughter's experience of distress?
How well do you feel you understand your son's/daughter's distress?
What have you found to be the most helpful ways of managing your child's distress?
Can you tell me about any resources or support that you have found beneficial or would have liked to have been offered?
What advice would you give to other parents of children with cancer about managing their children's distress?

Supplementary Information Table 2

Coding tree with major themes and codes

Theme	Codes
The contagion of distress	Accepting parental distress
	Justifying parental distress
	Unpredictability of adolescent distress
	Limited parental ability to manage adolescent distress
Navigating breaking point	Parental distress is inferior to adolescent distress
	Surrendering to parental distress
	Suppressing parental distress
	Perception of parental support availability
	Distress beyond parental capacity
Developmental disruption	Adolescent's regression to childhood
	Adolescent's acceleration to adulthood

	Parents sense of loss for adolescents missing normative experiences
	Adolescent's distress impact on parenting approach